Advance Care Plan (ACP 預設醫療計劃)
Do-Not-Attempt-Cardiopulmonary Resuscitation
(DNACPR不作心肺復甦術)

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Agenda

* Advance care plan預設醫療計劃
* Advance directive預設醫療指示
* DNACPR不作心肺復甦術

Story of Janice…

* Janice, 4mon, first child
* Refractory epilepsy since day 3 of life, on 4 anti-epileptic drugs, daily seizure
* Genetically confirmed congenital epileptic syndrome
* Global developmental delay, no response to surrounding
* N/G tube feeding
* Need oxygen supplement
* Refer Palliative Care

Advance Care Plan (ACP)

Advance Directive (AD)
(預設醫療指示)

* a document with ***legal status*** which the patient can *specify the treatment(s) that he/she is going to refuse (eg. CPR, NG feeding, IVF, etc)* in case he/she becomes mentally incapacitated to make decisions with disease progression

* Patient **>/= 18 years old** and **mentally competent**

* Can't refuse basic care: O2, oral feeding, pain control…

- **Advance care planning (ACP)**
  - process of communication on ***care goals and life-sustaining treatments*** with health care providers, patient and his/her family members/caregivers

- ***Not legally binding***

Why need ACP?

Why need ACP?

* ***Better communication*** among patient, relatives and medical staff
* ***More time to think***
* ***Consensus building***
* ***Better prepared emotionally*** for future deterioration of the patient's condition

When and who to initiate ACP?

* The appropriate time for triggering the ACP discussion depends on the state of the diseases and the readiness of the patients and the family members

* An ***anticipated deterioration*** in the individual's condition in the future

* Initiate by any doctor (nurse) who had received training on ACP and is competent

HA Guidelines on Advance Care Planning

Version	Effective Date
1	10 June 2019

Who should be involved in ACP discussion?

Parent =/- child

Other significant family relatives

Medical team: doctor, nurse, MSW, CP

Scope of discussion in ACP

Categories	Content
Disease	Diagnosis, prognosis
Treatment	Goal of care Options of treatment, side effect, outcome
Patient/parent	Values, believes, wishes Worries
Place of care/death	Home, school, hospital
Emergency care plan	What to do & not to do DNACPR

Appendix 1

醫院管理局 HOSPITAL AUTHORITY	**Advance Care Planning (ACP) For Mentally Competent Adult** (Original copy to be kept by the patient)	*Please affix gum label with address* Name: Sex/Age: ID No.: Ward/Bed: HN: Dept:

Points to note:

1. *This document is a record of my wishes and preferences. It helps the health care team understand what matter most to me and guide the future medical care and treatment. It is not a record of my advance decisions and is not legally binding.*
2. *If I wish to document my advance decision for refusal of any specific treatment, I have to sign an Advance Directive (HA-short AD form or HA-full AD form), which will be a legally binding document.*
3. *The health care team is not obliged to provide medically futile or inappropriate treatment irrespective of my preferences.*
4. *I may choose NOT to complete any particular items within sections 5 to 8.*
5. *If I change my preferences, I should discuss with my health care team and my family, and fill in a new ACP form.*

(1) Medical condition

Diagnosis

Prognosis (expected disease progression and prognosis as communicated with the patient)

Treatment

Appendix 2

醫院管理局 HOSPITAL AUTHORITY	**Advance Care Planning (ACP) For Mentally Incompetent Adult** (Original copy to be kept by the family)	*Please affix gum label with address* Name: Sex/Age: ID No.: Ward/Bed: HN: Dept:

Points to note:

1. *This document helps to increase understanding of the patient and guide the healthcare team in providing care and treatment for the patient. It is not legally binding.*
2. *The final decision of providing or withholding medical treatment will be based on the best interests of the patient with reference to the information in this document.*
3. *Medically futile or inappropriate treatment will not be administered even if it is believed to be the patient's preference.*
4. *I/we may choose NOT to complete any particular items within sections 5 to 7.*
5. *If I/we change my/our views, I/we should discuss with the healthcare team, and fill in a new ACP form.*

(1) Medical condition

Diagnosis

Prognosis (expected disease progression and prognosis as communicated with the family)

Treatment

醫院管理局
HOSPITAL AUTHORITY

Advance Care Planning (ACP) For Minor

(Original copy to be kept by the family)

Please affix gum label with address

Name: Sex/Age:

ID No.: Ward/Bed:

HN: Dept:

Points to note:

1. *This document helps to increase understanding of the patient and guide the healthcare team in providing care and treatment for the patient. It is not legally binding.*
2. *The final decision of providing or withholding medical treatment will be based on the best interests of the patient with reference to the information in this document.*
3. *Medically futile or inappropriate treatment will not be administered even if it is believed to be the patient's or family member's preference.*
4. *I/we may choose NOT to complete any particular items within sections 5 to 8.*
5. *If I/we change our views, I/we should discuss with the healthcare team, and fill in a new ACP form.*

(1) Medical condition

Diagnosis:

Patient (understanding of the illness):

Parents/family (understanding of the illness):

Prognosis:

Patient (understanding of disease progression and prognosis):

Parents/family (understanding of disease progression and prognosis):

Treatment

A minor, who is mature enough as to have sufficient understanding and intelligence, discussion should involve both minor and parents

Scope of discussion in ACP

(5) Values, beliefs and wishes of the parents/family, and of the patient to the best of my knowledge (if applicable)
From my/our understanding, things valuable to the patient include: (e.g. family, functional independence, spiritual or religious belief, funeral, pets etc)
From my/our understanding, things worrying the patient or the parents/family include: (e.g. dying in pain, unpleasant past medical experience, being a burden, lingering death, aftermath etc)
From my/our understanding, wishes or personal goals of the patient or wishes of the parents/family regarding the patient that are useful to share with others include:

(7) Preferences regarding limits on life-sustaining treatments[1] (by consensus between the parents/legal guardian and healthcare team according to the patient's best interests)

(a) When the patient's **life expectancy is limited and condition is deteriorating**:

☐ Prefer not to give life-sustaining treatments if possible.

☐ Prefer life-sustaining treatments even if the chance of success is low.

☐ The overall preference is between the above two. Specific preferences, if any, are indicated below.

- Specific preferences (which are not legally binding) for life-sustaining treatments are as follows:

Prefer not to give:	Not sure of the following:	Accept the following when needed:

☐ Not decided yet.

[1] "Life-sustaining treatment" means any of the treatments which have the potential to postpone the patient's death and includes, for example, cardiopulmonary resuscitation, artificial ventilation, blood products, pacemakers, vasopressors, specialised treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection, and artificial nutrition and hydration.

Appendix to ACP Form for Minor

Suggested Items for Discussion on Treatment Preferences During Emergency Situation/Last days of life for Paediatric Palliative Care Patients

Prepared by COC in Paediatrics

1. Transfer to PICU?

2. Respiratory Support:

- Oxygen mask bagging
- Non-invasive ventilation (BiPAP, CPAP)
- Intubation and invasive ventilation

3. Cardiac Support:

- Chest compressions
- Resuscitation medications, e.g. adrenaline, inotropes
- Electrical cardioversion

4. Fluids and Nutrition

- Tube feedings (NG tube)
- Parenteral nutrition

5. Medications:

- Antibiotics (oral or intravenous)
- Others:

6. Others:

- Blood taking
- Venous access (eg. peripheral long line, attempts of setting venous access)
- Dialysis
- Blood products
- Special preferences from patient/family

Advance Care Plan (ACP)

* Original copy of the ACP form or DNACPR form for non-hospitalised patients, if any, should be **kept by the patient/family**

* Advance care plan is **regularly reviewed** and there are changes in the values, wishes, preferences or advance decisions, a new ACP form should be filled in

* **Putting plans to action:** Values, wishes and preferences documented during the ACP should be taken into account,

ACP of Janice

* **Disease & prognosis:** refractory epilepsy, incurable, short life
* **Goal of care**
  * *Less suffering, less pain*
* Wishes, preference:
  * Prefer stay in hospital
  * wishes : *go home leave on mother's birthday*
* Make plans on
  * Future medical or personal care
  * Emergency care plan, Life-sustained treatment (+/- DNACPR)

Appendix to ACP Form for Minor

Suggested Items for Discussion on Treatment Preferences During Emergency Situation/Last days of life for Paediatric Palliative Care Patients

Prepared by COC in Paediatrics

1. Transfer to PICU?	No
2. Respiratory Support: ➢ Oxygen mask bagging ➢ Non-invasive ventilation (BiPAP, CPAP) ➢ Intubation and invasive ventilation	Only O2
3. Cardiac Support: ➢ Chest compressions ➢ Resuscitation medications, e.g. adrenaline, inotropes ➢ Electrical cardioversion	Not decide yet
4. Fluids and Nutrition ➢ Tube feedings (NG tube) ➢ Parenteral nutrition	No IV if possible
5. Medications: ➢ Antibiotics (oral or intravenous) ➢ Others:	Oral antibiotic only
6. Others: ➢ Blood taking ➢ Venous access (eg. peripheral long line, attempts of setting venous access) ➢ Dialysis ➢ Blood products ➢ Special preferences from patient/family	No PICC, max 3 attempts of venous puncture

Do-Not-Attempt-Cardiopulmonary Resuscitation (DNACPR)

醫院管理局 HOSPITAL AUTHORITY	Patient Safety & Risk Management Department / Quality & Safety Division	Document No.	CEC-GE-6
		Issue Date	20 January 2016
	HA Guidelines on Do-Not- Attempt Cardiopulmonary Resuscitation (DNACPR)	Review Date	20 January 2019
		Approved By	HA CEC
		Page	Page 1 of 31

HA Guidelines on Do-Not-Attempt Cardiopulmonary Resuscitation (DNACPR)

Version	Effective Date
1	6 October 2014
2	20 January 2016

醫院管理局 HOSPITAL AUTHORITY	Patient Safety & Risk Management Department / Quality & Safety Division	Document No.	CEC-GE-7
		Issue Date	22 September 2015
	HA Guidelines on Life -sustaining Treatment in the Terminally Ill	Review Date	22 September 2018
		Approved By	HA CEC
		Page	Page 1 of 49

HA Guidelines on Life-Sustaining Treatment in the Terminally Ill

Version	Effective Date
1	April 2002
2	1 December 2015

Anchoring on Section 34 on Care of terminal ill in the Professional Code & Conduct Of Medical Council of Hong Kong (MCHK)

醫院管理局
HOSPITAL AUTHORITY

Hospital Authority
Do Not Attempt CPR (DNACPR)
For Hospitalized Patients
住院病人「不作心肺復甦術」文件

Patient's Gum Label
(Patient's Gum Label should contain the patient's name, sex, date of birth, and HKID)

I. Diagnosis:

II. Current Condition:

☐ Terminal illness ☐ Poor response to optimal therapy ☐ Profound neurological damage

☐ Others :_____

III. Communication on DNACPR, or previous decision on DNACPR:

☐ Explanation on DNACPR provided to patient/relatives,

For mentally competent patient: ☐ DNACPR accepted by patient

For minor or mentally incompetent adult : ☐ DNACPR accepted by relative(s)
Relatives (names & relationship to patient): ……

☐ The patient is mentally incompetent and has no family members

☐ The patient has a valid DNACPR form for non-hospitalized patients (copy of the form attached)

☐ The patient is transferred from another hospital for continuation of in-patient stay and has a valid DNACPR form for hospitalized patients (copy of the form attached)

Other remarks:

IV. Decision on DNACPR:

When the named patient develops cardiopulmonary arrest, **NO CPR** (neither artificial ventilation, external cardiac compression, nor defibrillation) should be given for the following reason(s):

☐ he/she is unlikely to benefit from **CPR**
☐ **CPR** is against his/her wish

However, all other appropriate treatment will be provided.

V. Signatures of healthcare team doctors (please see notes at the back of the form):

Doctor:	Specialist doctor:	
Name:_____	Name: _____	
Signature:_____	Signature:_____	Department: _____
Date: _____	Date: _____	Hospital: _____

VI. Review (please see notes at the back of the form):

Date	Doctor		Department	Continue DNACPR? (please tick)		
	Name	Signature		Yes	No	
						Please cross out this form if DNACPR is revoked

致：急症室醫護人員

請填寫英文部份或中文部份

醫院管理局 HOSPITAL AUTHORITY	非住院病人 「不作心肺復甦術」文件	請以正楷書寫或貼上病人標籤 入院／門診號碼：..... 姓名(英文)：..... (中文)..... 身份證號碼：.....性別：....年齡：.... 部門：.....組別：.....病房／床號：..../.....

I. **診斷:**

II. 吾等是核證醫療團隊的醫生，在簽署本文件第 IV 部分之日，我們
(請選擇填寫下文(A)或(B)段)：

(A) *有預設醫療指示的成年人:*

確認病人於_____(日期)簽署的預設醫療指示為有效，病人拒絕接受心肺復甦術；及

證明病人的臨床情況符合預設醫療指示所述(請加✓號)，即：

- ☐ 病情到了末期；
- ☐ 處於不可逆轉的昏迷或持續植物人狀況；
- ☐ 有其他晚期不可逆轉的生存受限疾病：_____；及

根據該預設醫療指示，若病人處於預設醫療指示所述的情況，並出現心肺停頓，便不要為病人施行人工輔助呼吸、心外壓程序或心臟除顫。

(B) *沒有有效預設醫療指示的精神上無行為能力成年人或未成年人士：*

證明病人(請加✓號)

- ☐ 病情到了末期；
- ☐ 處於不可逆轉的昏迷或持續植物人狀況；
- ☐ 有不可逆轉的主要腦功能喪失及機能狀況極差；
- ☐ 若為未成年人士，有其他晚期不可逆轉的生存受限疾病；

以及

病人的現今臨床狀況及預設臨終照顧計劃已為有關人士討論：
(請加✓號)

- ☐ 照料病人(屬精神上無行為能力的成年人)的醫療團隊與病人家屬曾作討論
- ☐ 照料病人(屬未成年人士)的醫療團隊與病人父母曾作討論

並且

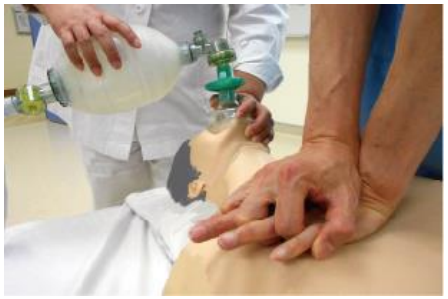
已達致共識，若病人出現心肺停頓，最符合病人利益的做法，是不要為病人施行人工輔助呼吸、心外壓程序或心臟除顫。

病人家屬(或父母)確認同意病人「不作心肺復甦術」的決定(只適用於(B)段)。

簽署:_____ 日期: _____

What is Cardiopulmonary Resuscitation (CPR)?

* **CPR** is the invasive medical therapy to support ventilation and circulation when cardiac arrest occurs:
  * **(1)** chest compression
  * **(2)** assisted breathing
  * **(3)** artificial ventilation
  * (4) attempt defibrillation with electric shocks, injection of drugs



Do-Not-Attempt-Cardiopulmonary Resuscitation (DNACPR)

* An **elective decision** not to perform CPR
* ***made in advance***
* ***CPR is against the wish of patient*** or ***CPR is not in the best interests of patient***

* Terminal illness
* Irreversible coma or persistent vegetative state
* Irreversible loss of major cerebral function and extremely poor functional status
* Other end-stage irreversible life limiting condition, further treatment is more than can be borne

* **DNACPR not automatically imply forgoing other life-sustaining treatments**

Do-Not-Attempt-Cardiopulmonary Resuscitation (DNACPR)

* For a mentally competent adult, patient's informed decision
* A valid advance directive (AD)
* For a minor, health care team should build ***consensus with parents*** and, where appropriate, ***the minor*** as to be in the best interests of the minor

Communication

* Not to ask the patient or family members to make a decision on CPR, but to provide clinical information ***for them to understand that CPR is not in the best interest of pateint, prolong the dying process and suffering***

* Understand the possibility of dying

Communication

* Emphasize that patient **will not be abandoned.** All appropriate treatment, eg. Comfort care, will be provided

* Ensure that patient/family ***can change their minds*** or seek further information

* ***Record*** the communication in case note

Communication

* If the patient or family members do not want to receive information or continue discussion, the communication should not be forced

* Arrange another interview

Communication with minor

* A minor, who is mature enough as to have sufficient understanding and intelligence to understand a DNACPR, decision should involve both minor and parents

* Should be communicate in a language that is appropriate to his developmental status

* The choices of minor patients with sufficient decisional capacity and maturity to consent to or refuse what had been proposed should be taken very seriously unless the choices are clearly not in their best interests

Conflict

* ***explore*** the underlying reasons, align expectations, clarify misconception or misunderstandings
* Disagreement resolved by ***further communication***
* More experienced colleagues, case conference, local ethic committee, legal advice
* ***Patient/family cannot insist on treatment that doctor deems inappropriate, not as the best interest of patient***

DNACPR recommendation for the receiving team

* The DNACPR decision/form should be reviewed at least every 6 months, or when there is a change in clinical condition
* Flag an alert in CMS who has a completed DNACPR form for non-hospitalized patients
* Should ascertain that the decision of DNACPR remain valid and unchanged

Safe Guard

* If in doubt, or if foul play, accident or untoward event is suspected, CPR should be given for patient's best interest

* If cardiac arrest is from a potentially reversible causes, eg. Choking, induction of anaesthesia, anaphylaxis or blocked tracheostomy tube, CPR may be appropriate even a DNACPR decision is established

Back to Janice…

* *Janice's father agrees on **DNACPR** whereas mother does not*

Back to Janice…

* *Janice's father agrees on DNACPR whereas mother does not*
  * explore the underlying reasons, align expectations, clarify misconception or misunderstandings

Back to Janice…

* *Janice's father agrees on DNACPR whereas mother does not*
  * explore the underlying reasons, align expectations, clarify misconception or misunderstandings
    * ***Mother heard the new treatment in SMA and hoped for new genetic treatment on Janice***
* Disagreement resolved by further communication

Story of Janice

* Severe RSV pneumonia
* Mom became panic, requested PICU care

Appendix to ACP Form for Minor

Suggested Items for Discussion on Treatment Preferences During Emergency Situation/Last days of life for Paediatric Palliative Care Patients

Prepared by COC in Paediatrics

1. Transfer to PICU?	No → admit PICU
2. Respiratory Support: ➢ Oxygen mask bagging ➢ Non-invasive ventilation (BiPAP, CPAP) ➢ Intubation and invasive ventilation	Only O2 → HFO2
3. Cardiac Support: ➢ Chest compressions ➢ Resuscitation medications, e.g. adrenaline, inotropes ➢ Electrical cardioversion	DNACPR unchange
4. Fluids and Nutrition ➢ Tube feedings (NG tube) ➢ Parenteral nutrition	IV fluid & morphine/midazolam infusion
5. Medications: ➢ Antibiotics (oral or intravenous) ➢ Others:	Oral antibiotic only
6. Others: ➢ Blood taking ➢ Venous access (eg. peripheral long line, attempts of setting venous access) ➢ Dialysis ➢ Blood products ➢ Special preferences from patient/family	No PICC, max 3 attempts of venous puncture

Story of Janice

* Transferred to PICU, on high flow O2
* Revisit the DNACPR decision
* Given morphine and midazolam infusion
* Passed away peacefully in mom's arms

Take Home Messages

* ACP is a process of communication on ***care goals and treatment plans***
  * ***Better prepared emotionally*** for future deterioration
  * ***Early introduction*** *is advised*
* DNACPR in palliative care cases, we should provide clinical information ***for family to understand that CPR is not on the best interest of the patient***
* For Minor who is mature enough as to have sufficient intelligence, should be involved in the ACP & DNACPR discussion. Their choices of treatment should be considered seriously.
* Disagreement resolved by further communication

晚期治療照顧計劃你有*Say！*

- 9/2019食物及衞生局
- 公眾諮詢文件
- 晚期照顧：有關「預設醫療指示」和病人在居處離世的立法建議

Raising awareness of children's palliative care, one hat at a time!

icpcn

international children's palliative care network

#HATSON4CPC

Thank You !